Is a Lack of Research Masking Barriers to Equitable Health for Deaf British Columbians?

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Abstract

The Canadian health information and healthcare systems are largely designed around both aural and visual mediums, likely excluding Deaf British Columbians. Yet, little research exists on the health of this community or on barriers they may face in obtaining equitable access to healthcare and health information. Drawing on national and international data, potential barriers for Deaf British Columbians are examined, highlighting a need for culturally safe research in this area in order to identify, examine and reduce barriers faced by this community and, ultimately, improve health equity in this population.

***AN ACCESSIBLE (ASL) EXECUTIVE SUMMARY FOR THIS ARTICLE IS AVAILABLE HERE: https://www.youtube.com/watch?v=dTaJxCCe_Xg&feature=youtu.be

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1. Introduction

Health in Canada, similar to many other things, is not equally distributed (Bryant, Leaver, and Dunn 2009, 25-26). Systems and society provide some with greater health, while others face significantly more barriers to equitable health (Raphael 2006, 653-654). In a society that is designed around both the senses of vision and hearing, the Deaf community faces significant barriers to equitable health.

The Deaf community is a unique cultural and linguistic group (Reagan 1995, 243-245; Padden and Humphries 2005, 1-5). In this article, a distinction will be made between the medical definition of deafness and the cultural and linguistic identity, with 'deaf' referring to a loss of hearing and 'Deaf' referring to those who identify as a cultural and linguistic group. Many of the Deaf community members' first language is American Sign Language (ASL), a grammatically and linguistically distinct language from English (Valli and Lucas 2000, 14; Emmorey et al. 2008, 43-44). As such, many members of this

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community should be considered second language users of English. Like many linguistic and cultural minorities, and second language users of English, the Deaf community face barriers to health information and healthcare. In this paper, these barriers are understood as a failure of health systems to provide adequate and relevant services rather than as a result of being Deaf. This is similar to the social model of disability that highlights the disabling effects of the design of physical and social systems (Shakespeare 2006, 198-199).

In order to highlight the barriers that Deaf British Columbians face in obtaining equitable access to health information and health care, this paper draws on diverse research. Ultimately, in order to provide equitable health to this community, it is argued that culturally safe research is needed in order to better understand, identify and reduce barriers Deaf British Columbians face.

2. Barriers to Healthcare

Deaf people in British Columbia are often unable to access primary or specialist medical healthcare providers who are fluent in their language. Though it should be noted that there are a few Deaf medical doctors (Russell 2015, 85-86), and no doubt some who are fluent in ASL, these are too few to provide sufficient service to a community of many thousands (Canadian Association of the Deaf 2015). As a result, Deaf people and their healthcare providers most often do not share a language nor a culture. While there are many approaches to bridging this gap, many practitioners and patients utilize interpreting services.

Professional medical interpreters have been shown to reduce the number of clinically significant communication errors as compared to untrained bilingual individuals or situations in which no interpretation services were utilized (Flores et al. 2012, 548). In other minority language communities, professional interpreter use has been generally shown to improve health outcomes and processes (Flores 2005, 292); improve patient satisfaction in mental health encounters (271); reduce re-admission rates in emergency care (Karliner, Pérez-Stable, and Gregorich 2017, 203; Lindholm et al. 2012, 1297); improve patient comprehension of medical consent (Lee et al. 2017, 866); and, in one study in a hospital emergency setting, to significantly reduce healthcare costs (Karliner, Pérez-Stable, and Gregorich 2017, 203). Moreover, specifically within the Deaf community in the United States, professional interpreter use was found to improve the reported quality of care received (Steinberg et al. 2006, 262) and comprehension of medical care instructions (Steinberg et al. 2002, 737-738). Yet, these interpreting services are not provided ubiquitously in all medical situations in British Columbia, nor have there been any extensive exploration of the impact of sign language interpreter mediated relationships in North America.

3. Potential Barrier: Lack of Universal Interpreting Services in Healthcare Settings

Within British Columbia, as a result of the Eldridge v British Columbia (1997) decision in which it was ruled that failure to provide professional sign language interpreting services in medical settings was in conflict to the Canadian Charter of Rights and Freedoms, the provision of professional medical interpreting services is provided at no cost to patient or practitioner by Provincial Health Services Authority within the services explicitly defined by the Canada Health Act (1984, s. 9). Specifically, professional medical sign language interpreter services can be accessed for "General practitioners (ie. family doctors) and specialists, Psychiatrists, Ophthalmologists, Gynaecologists/Obstetricians, Medical imaging and Hospital stays" (Western Institute of the Deaf and Hard of Hearing, 2017). No doubt this

has greatly improved the quality of care and reduced barriers to healthcare for Deaf British Columbians; yet, gaps remain in the provision of this vital service. Specifically, community-based dental, optometry, non-profit specialized health organizations, physiotherapy and pharmacy service providers are unable to access medical sign language interpreting services through the Provincial Health Services Authority program, leaving these healthcare providers to elect or decline to pay out-of-pocket on an individual basis. As a result, interpreting services are rarely if ever used in these situations.

Next, pharmacy services will be used as an exemplar in order to highlight the potential impacts and barriers brought about by a failure to fund medical sign language interpreting services in all healthcare service areas. Pharmaceuticals have become a large part of the provision and maintenance of health in our society (Romain 2013, 2). Pharmacy services help to mitigate adverse drug reactions (3), promote the effective use of medication (3) and provide advice on treatment options (3). Fundamental to the effective provision of pharmacy services is communication (Phokeo and Hyman 2007, 423; Romain 2013, 1). Yet, as second language users of English, many Deaf people have a reduced English medical vocabulary similar to that of non-English speaking immigrants (Steinberg et al. 2006, 264; Barnett et al. 2011, 1), making written communication an ineffective option for many Deaf patients. Unaddressed communication barriers interrupt patient-pharmacist relationship development and may lead to a lack of rapport and mistrust and, consequently, poor health outcomes (Ferguson and Shan 2015, 463). Indeed, one research study conducted in a children's hospital in the Pacific Northwest of the United States found that patients facing a language barrier were twice as likely to experience an adverse medication event then those patients who did not face a language barrier (Cohen, Rivara, Marcuse, McPhillips, and Davis 2005, 577). Similarly, an increased risk of side effects due to language barriers has been shown in community pharmacies as well (Schwappach, Meyer Massetti, and Gehring 2012, 766). Finally, without a clear and effective way to communicate with pharmacists, Deaf British Columbians face a lack of knowledge, and no way to report and discuss side effects, both of which have been shown to increase the risk of treatment abandonment and medication misuse (Romain 2013, 3; Schwappach, Meyer Massetti, & Gehring, 2012).

4. Potential Barrier: Lack of Knowledge on Effective Interpreter-Mediated Rapport Building

The relationship between healthcare providers and their patients is vital. A high-quality relationship has been shown to improve patients' adherence to treatment plans (Berry et al. 2008); specific health outcomes such as ischemic heart disease (Farin and Meder 2010, 5); and patient activation in those with chronic illness (Alexander et al. 2012, 1217-1218), which is associated with increased self-management (Hibbard et al. 2007, 1460). However, Deaf patients and physicians face additional complexity in establishing a high-quality relationship with each other as a majority of their interactions are navigated through an interpreter. The addition of an interpreter makes interactions "triadic" in nature, and thus more complex, as three people are actively attempting to communicate (Fatahi et al. 2008, 45). While it is likely that all members of this triadic relationship endeavor to promote healthy relationships, considering the multiple cultures and languages involved, it is possible that actions taken by one person with the intention of promoting positive rapport may be perceived negatively by other members of the medical encounter.

Medical Sign Language Interpreters are unable to produce a word-for-word interpretation, as ASL and English are unique languages with little overlap. Instead, sign language interpreters, most often, work from a meaning-based paradigm, using their skills and life experience to reproduce the emotions, purpose, style and meaning of utterances from one language into the other (Janzen 2005, 8-10). As such, while the information provided by practitioner or patient is likely to be interpreted similarly in content,

how the utterance is presented and structured is likely to change between different medical sign language interpreters. Often medical appointments between the same practitioner and patient are interpreted by different medical sign language interpreters. The unique ways that each medical sign language interpreter presents and structures information when moving from one language to the other may affect the healthcare practitioners' perceptions of the Deaf patient, which has been shown to affect the care decisions they make (Thom et al. 2011, 153). Alternatively, it might be that the novel presentation of the same information could make it seem like new information, again adding to the complexity of an already complex triadic medical interaction. At the least, this points towards the need to better understand this aspect of navigating healthcare relationships through professional medical sign language interpretation services.

Interpreted medical interactions represent an interdisciplinary team approach to medical care where Deaf patients, physicians and interpreters must work together in order to provide holistic and effective medical care (Canadian Interprofessional Health Collaborative 2010, 6). If we understand it through this framework, then in order to be effective, all members of the interdisciplinary team need to be able understand each other's role, responsibilities and scope of practice, among other fundamental skills (9). However, the effectiveness of such teams and the care they provide may be compromised without research—such as culturally safe research about Deaf patients—to aide in the development of these competencies within all members.

5. Barriers to Health Information

Individual and community health is supported by a great number of things beyond just healthcare provision, including the health-related information we are able "to access, understand, evaluate and communicate", commonly called health literacy (Rootman and Gordon-El-Bihbety 2008, 11). With improved health literacy, patients can better navigate healthcare relationships, manage chronic illness and avoid preventable diseases (Rootman and Gordon-El-Bihberty, 2008, 3). In contrast, low health literacy is associated with poor health and increased medication errors (Mitic and Rootman 2012, 11). Fundamental to obtaining health literacy is access to clear and quality health information. Unfortunately, barriers exist for Deaf British Columbians in accessing such health information.

Deaf people miss out on a large amount of the incidental health information that non-deaf people are exposed to in their everyday lives (Job 2004, 265). Overhead conversations throughout our lives provide a significant amount of health information, however, these conversations are often inaccessible to Deaf people (265-266). Moreover, direct and indirect family conversations are often a source of not only important health information but of specific family health histories (266). Yet, the majority of Deaf people are born to non-deaf family, with many of these non-deaf families not obtaining a high level of fluency in ASL (266). This effectively interrupts the intergenerational transmission of health knowledge and family medical history (Barnett et al. 2011, 1).

Deaf British Columbians also face barriers in accessing more formalized sources of health information. British Columbian public health websites and services such as HealthLink BC, the Center for Disease Control B.C and public health announcements are, at present, not translated or interpreted into American Sign Language, further excluding a community that is already disadvantaged due to reduced incidental information exposure. While it is noteworthy that efforts are being made to support the health information development in spoken language minority communities via language specific services and translations, such as those seen on Healthlink BC homepage, the absence of such services

for ASL users may speak to a fundamental misunderstanding of the nature of American Sign Language. Without exposure, many people assume ASL is English represented in another modality, rather than a unique language fundamentally different from English.

These barriers to health information decrease the opportunity for Deaf British Columbians to develop health literacy. The long term effects of reduced health literacy on minority community health cannot be underestimated: indeed, one study conducted in the United States found that the Deaf people sampled were 6.9 times more likely than the general population to have low health literacy (McKee et al. 2015, 5). And, in one qualitative study in Newfoundland, the sample of Deaf people reported being largely unaware of palliative care or the scope of the services available to them (Maddalena, O'Shea, and Murphy 2012, 108). No doubt, this lack of awareness increases the likelihood of members of this community experiencing unnecessary suffering.

6. Recommendations for the Reduction of Barriers

Limited research exists on the barriers to healthcare and health information that Deaf British Columbians or Deaf Canadians face. Without a foundation of relevant local research, the barriers faced by Deaf British Columbians are unlikely to be identified, understood and ultimately, reduced. In a fiscally-limited healthcare system, it is important to ensure that interventions to reduce barriers be well-researched in order to ensure effectiveness. While international research on Deaf communities, such as those from the United States, might be utilized to inform the design of local research, differences in healthcare systems and community demographics make assumptions of parallelism reductionistic and perhaps even dangerous.

Based on the information explored thus far, in order to promote equitable health in the Deaf community in British Columbia, it is recommended that culturally safe research be funded and conducted to better understand the healthcare and health information experiences of this community. In particular, it is recommended that initial research be focused on the topics of: triadic patient-practitioner rapport as mediated through medical sign language interpreters; the best avenues to provide health information to Deaf British Columbians; and the effects of the lack of access to medical sign language interpreters in healthcare services outside of those explicitly outlined in the Canada Health Act (1984). This research should be thoughtful of Deaf community members who are members of multiple marginalized populations, as it is likely that these individuals face additional barriers and marginalization.

This research agenda should be modified and refined through community consultation with the Deaf community in British Columbia. The Deaf community have a lifetime of experience to draw on, making them an ideal resource for developing a research agenda. The barriers identified in this paper might serve as a starting point for discussion, but should be discarded or refined based on community feedback and opinion. Using the Deaf community's expertise to identify challenges they face regularly and on mass, researchers might avoid assumed barriers.

A growing area of consideration in intercultural research is the need to maintain cultural safety throughout the research process. Cultural safety can be understood as: socially just research designs and processes that are intended to provide a safe and meaningful environment and research outcomes for the community of focus (Lynam and Young 2000, 8). Research including the Deaf community should be designed with cultural safety at its heart, beginning with the appropriate consideration of cultural and linguistic factors in the development of research questions (Singleton, Jones, and Shilpa 2014, 62-63).

Singleton, Jones, and Shilpa (2014) should be consulted as they highlight several important factors in creating socially just research within the Deaf community.

Each research study needs to consider cultural safety uniquely, but it is recommended, in the short term, that cultural safety might be best ensured by diverse Deaf advisory committees overseeing, guiding, and advising on research. Another suggestion worth considering is Deaf community advisors functioning as research "gate-keepers" (Singleton, Jones, and Shilpa 2014, 62), protecting their community from non-culturally or linguistically-informed research and researchers (62). Whenever possible, current Deaf researchers and health professionals should be recruited to be primary investigators in these studies (63). In the long-term, efforts should be made to ensure that Deaf community members themselves are able, supported, and encouraged to become health researchers in various health organizations (Barnett et al. 2011, 3).

7. Conclusion

There is sufficient literature and data from both national and international studies to suggest that Deaf British Columbians face barriers to health information and healthcare, likely resulting in inequitable health. Yet, there is insufficient information and data to understand the specifics of these barriers and how they might be addressed. If we are to build healthcare and social systems that support the health of all British Columbians, then we need to build a strong base of research in order to effectively reduce barriers faced by the Deaf community. The community itself might best inform a research agenda and should be considered a significant resource in addressing barriers. Only through the recognition of this unique cultural community, research and the subsequent reduction of barriers can we hope to provide equitable health to Deaf British Columbians.

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